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ABSTRACT

Following the birth of a handicapped child, both parent and grandparent experience similar feelings of consternation, shock, and grief. The grandparents' reaction is double, however, as they suffer not only for the newborn but for their own child's pain as well. This article focuses on dealing with grief and its stages, including numbness, denial, anger, guilt, blame, depression, anxiety, and acceptance. Suggestions are offered on developing fulfilling relationships between parent and grandparent, and between grandparent and grandchild; and the best ways for the grandparent of a special grandchild to provide support. Tips for parents include being honest, asking for help, and educating the grandparents. Tips for grandparents include using leisure time to the grandchild's best advantage and providing gifts appropriately. (JDD)

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Special Parent Special Child

VOL. 6, NO. 2 MARCH/APRIL 1990

FOCUS ON GRAND-PARENTS

The impending birth of a child fills the entire family with anticipation and delight. The hopes and joys of the prospective parents and grandparents are cruelly dashed, however, when the eagerly-awaited infant is born with problems. The most heart-rending task of all falls to the new parent who must break the news to the grandparents that the child has been born handicapped. *Both parent and grandparent experience similar feelings of consternation, shock and grief.* The grandparents' reaction , however, is *doubled*—the grandparents suffer not only for the newborn but for their own child's pain as well. As the grandparent of a grandchild born with cerebral palsy commented, "I worried, of course, about the welfare of my grandchild, but my heart broke even more for my son and daughter-in-law—for what they were going through and for not being able to experience the normal joy of becoming a parent."

In this issue we will focus on dealing with grief; how to go on to develop fulfilling relationships between parent and grandparent, grandparent and grandchild; and the best ways for the grandparent of a special grandchild to provide support.

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Initial reactions

Both parent and grandparent share the universal reactions of grief. The initial reaction to the birth of a handicapped child is usually *numbness.* The numbness is an *actual* physiological response, and is nature's way of protecting us from feeling unbearable pain. This short-lived stage gives us time to develop ways of coping.

The most frequent coping mechanism that follows is *denial.*

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Feelings of unreality, that this really didn't happen or is some kind of a mistake, are common examples of this stage. Grandparents who are removed from first hand experiences with the newborn or who live at a distance frequently cling to denial reactions, hoping against hope that their grandchild is somehow miraculously outgrowing the defect. In extreme situations the grandparent may avoid visiting or even telephoning, thus not having to come to terms with the painful truth. Unfortunately, this type of behavior can be mistaken for disinterest, compounding the new parents' sorrow and robbing them of much needed support.

Grief reactions

It is important to recognize that clinging to denial is one way of not having to grieve. Persistent denial, as understandable as it is, will only backfire because we *must* grieve in order to heal. Grief is the natural expression of all the emotions we feel when faced with tragedy. Not allowing oneself to feel these tremendous pangs can often result later on in serious depression, stress-related physical illness, insomnia and other emotional problems. Paradoxically, the only way to relieve grief is to permit the sorrow and pain to surface. Feelings of grief shared with someone else—spouse, counselor, clergyman—gradually lessen in duration and intensity. Grandparents who believe they are being strong by denying or suppressing their grief feelings run the risk of compromising their ability to function and be of any assistance.

Very often the grandparents and new parents are unable to communicate to each other exactly how they feel. Both sides may feel vulnerable or wish to protect each other. However, sharing feelings honestly and openly will bring the family closer together. Sympathetic words or tender encouragement can go a long way at this point.

One of the most frequent reactions to tragic circumstances is *anger.* This can be a generalized response such as "Why did this happen to me?" or can be directed to others such as the doctor or the hospital where the child was born. Anger in its extreme form can manifest itself as uncontrollable rage, thus paralyzing and frightening at the same time.

Misplaced anger. Frequently anger is displaced and serves as a way of assigning blame to others, especially to the doctors and therapists. At times misplaced anger is directed towards the handicapped child for being handicapped and this unhappy situation can result in rejecting the child altogether.

Unfortunately, there is no easy answer to dealing with anger. Although anger is understandable it is ultimately non-productive. As one young parent told the grandparents, "My anger went away when one day I looked down at my child and thought not 'Why me?' but 'Why him?'"

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Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

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Of all the reactions, **feelings of guilt and blame** are the most cumbersome. Comments from other family members—"this never happens on our side of the family"—only add more distress. In some cultures the birth of a child with a handicap is seen as a form of punishment for something that happened in the past, even in a previous life! Some parents and grandparents feel that having a disabled child is a sign of weakness or inherent imperfection even when this is patently untrue.

Guilt or laying blame serves no purpose; it shuts out the world and closes off avenues of help. Grandparents can play a major role in assuaging unfounded guilt by assuring the young parents that laying blame at their doorstep is unthinkable.

Depression and anxiety are other reactions that can occur and reoccur. The best way to deal with depression is to recognize that sad feelings are justifiable under the circumstances. Active involvement in the child's welfare usually dispels the gloom or lessens the intensity. However, when the depression is generalized pervasive or extreme, professional intervention is indicated.

Acceptance is the last, hoped-for stage in the grief process. Although sorrow over the event never disappears entirely, the unhappy feelings do lessen in intensity as time passes. There is a more positive side to the picture for, as the child grows, parents and grandparents alike have the opportunity to experience joy and pleasure *just as with any other child.*

As one grandmother commented, "Although I can never completely accept the fate that has befallen my children it doesn't get in the way of the love we all feel for my little granddaughter. Somehow that makes the reality of the situation not as grim."

Tips for parents

In most cases grandparents with a handicapped grandchild want to shoulder some of the burden and help out as best they can. Sometimes they are so overwrought themselves they get carried away and their good intentions become overbearing or interfering.

Be honest. If you feel the grandparents are out-of-bounds, let them know as calmly and gently as possible what the problem areas are.

If, on the other hand, you feel the grandparents have distanced themselves, perhaps because they don't wish to get in the way, then let them know you welcome their inquiries and visits. In any event, open communication and an honest expression of wants and needs work best. If the grandparents ask how they can help, tell them as explicitly as possible: Can you food shop? Take the other children for the weekend? Take my car in to be serviced? Suggest whatever will make things easier. Most grandparents would be delighted with a little bit of direction.

Asking for help. Subtle hints often lead to misunderstandings and hurt feelings. If you are in need of financial assistance, for example, *discuss this openly.* In many cases young couples with an infant or young child strive to be as independent as possible. However, having a handicapped child

can strain both financial and emotional resources. Being honest about your situation and your feelings is the best bet, whenever asking for needed assistance.

Educate your parents about their grandchild's handicap. Send them literature, pamphlets or books about the specific disability. Have them accompany you and their grandchild to the child's doctor, therapist, special school or clinic. Let them ask the doctor or teacher questions so they can learn *firsthand* the nature and extent of the grandchild's needs. The more educated the grandparents become, the better able they are to help you *and* their grandchild. Sometimes grandparents have hidden fears or misconceptions about the nature and course of their grandchild's problem. Gaining knowledge can dispel many unfounded anxieties. The more grandparents know, the less likely they are to offer unwanted advice about "cures," diets and the like.

Help your parents to feel comfortable with caring for their grandchild. In many cases grandparents hesitate to babysit or provide respite because they are fearful of doing something wrong or harmful. Your explicit instructions and hints will enable the grandparents to relax, enjoy and bond with their grandchild. Giving grandparents the opportunity to hold close and nurture their grandchild deepens love and family ties.

Tips for grandparents

Most grandparents who have more financial resources and leisure time at their disposal find great pleasure in the relationships they develop and the activities they share with their grandchildren. In many cases grandparents have a more relaxed attitude towards their grandchildren; they are not as pressured or fearful of spoiling the child as when they were young parents themselves. Tales of doting grandparents who indulge their grandchild's every whim are legendary, however; allowing grandchildren forbidden sweets, staying up late or ignoring family rules, although prompted by the most loving of intentions, can create family friction—especially when the child has special needs. This is even more the case if the grandchild has special dietary restrictions or needs careful behavioral monitoring.

Grandparents can avoid hard feelings by sitting down beforehand and requesting careful explanations regarding their grandchild's care, including, for example, what activities are overstimulating, what activities are most beneficial, hints on handling and dietary needs.

By becoming as expert as possible the grandparent will be able to provide consistent care and help when and where it is most needed.

Use leisure time to your grandchild's best advantage. Because grandparents are removed from the day-to-day care of the handicapped child that can sap energy

and spirit, they are better equipped to do and say the little things that enrich the quality of their grandchild's life. The grandfather, for instance, who patiently tosses the ball back and forth to help with coordination, or the grandmother who spends hours teaching shoelace tying is providing a loving service that delights both grandparent and grandchild. The best gift a grandparent can offer is the gift of time.

Providing actual financial gifts, however, requires careful evaluation. Many well meaning grandparents leave bequests or send funds to their disabled grandchild not realizing that often this is *not* the best way to provide for the child's needs. In many states having funds in one's own right disenfranchises the disabled individual from vital services and benefits, including Medicaid, Social Security supplemental income (SSI), group home living and much more. Grandparents and parents should seek the advice of attorneys or agencies expert in the field before drafting wills, planning estates or giving sizable gifts. Regulations vary from state to state so it's a good idea to contact organizations such as the local Association for Retarded Citizens (ARC) or the local Bar Association.

Do's and don'ts

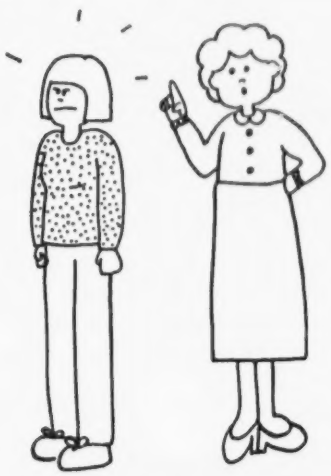
Do be aware that most schools, agencies and parent support groups welcome attendance by grandparents. Some associations even have grandparent groups. This is a good way of keeping abreast of your grandchild's specific disability and, more importantly, indicates your moral support.

Do avoid the pitfalls of cliché-ridden advice. Comments about God's will, or Pollyanna statements about things not being as bad as they seem sound condescending and don't provide the comfort you wish to imply.

Do remember that if you have a positive, tender, loving attitude towards your disabled grandchild, others in the family will feel the same way. The more support from family members, the better the young parents feel.

Do remember that non-verbal expressions—a loving pat to your grandchild's head, a warm hug to your son, daughter and their spouses—convey what words cannot express. By the same token pitying glances and an anxious tone of voice deepen gloom.

Do be aware of any heightened sensitivity in the parents. Be careful about what you say and remember that your most well intentioned remarks can be taken the wrong way. Handle this with grace and humor.



Do let your children know that they can rely on you in good times or bad. Many grandparents have flexible schedules that can be arranged to meet the needs of the grandchild. Just knowing that this kind of help is available can lessen anxieties and strengthen family bonds.

Do offer to visit or help out with your grandchild regularly. Sometimes staying at a nearby hotel can ease the logistics and make the visit even more rewarding for all concerned.

Do find out the best time for you to visit or telephone. Your children might relish their privacy or be in the middle of things and, unless you ask, your visits or telephone calls might come at an inconvenient time for them.

Don't allow any frictions between yourself and your children interfere with your relationship with your grandchild. The bonds of love between grandparent and grandchild are genuine and profound. The relationship can enhance and nurture the special grandchild's feelings of self-esteem and self-worth.

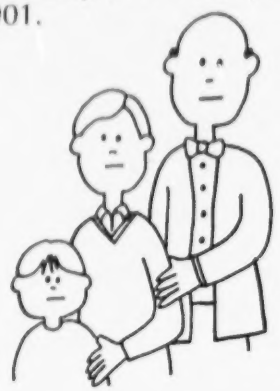
Do be aware that there are revolving cycles of grief. Feelings of depression, anger, non-acceptance or sorrow usually surface around birthdays or other milestones, such as when your grandchild should have been starting regular kindergarten or school. Knowing this ahead of time can prevent the reaction from becoming extreme.

Do remember that above all the relationship of a grandparent to a grandchild is unique, and the love that is generated is freely given and like no other. Your handicapped grandchild is first and foremost a child—more like other children than unlike. The needs of a special child differ only in degree, not in kind. Your special grandchild responds to your love, your jokes and games, your abiding affection exactly like any of your other grandchildren.

Parent-to-parent network: Fragile X Association of New York

The Fragile X Association of New York is an information and resource center for families of children with fragile X syndrome and the professionals who work with them. Fragile X syndrome is a genetic disorder that results in cognitive deficits, developmental and language delays, and behavioral problems. The association serves as a clearinghouse for published material on the disorder; publishes a newsletter, *Fragile Exchange*; is developing a network of providers who actually or potentially serve fragile X children; and is working to establish parent support groups.

For more information or to be placed on the association's mailing list, please contact the Fragile X Association of New York, 61 Dean Street, Brooklyn, NY 11201; 718-875-4901.



PSYCHOLOGIST'S CORNER

Compulsive behavior and your special child

by George Popper, Ph. D.

We've all known young children who cling to a doll or blanket and adults who have good luck charms or unusual rituals. For most of us these behaviors are usually harmless. They don't interfere significantly with our lives or intrude on others; normal children eventually give up their dolls and blankets as they grow older. Some special children *insist* on having things their way and have little tolerance for disruption of their own routines. Special children, however, are of concern because of the tenacity with which they cling to their compulsions and the way in which some of their behaviors interfere with their ability to learn, to grow and to develop.

Compulsions and rituals are distinguished from normal growth and development by the extent to which individuals are preoccupied with them. Truly compulsive individuals not only engage in compulsive behaviors, they are often seen as emotionally restricted and preoccupied with trivial rules to the point where they no longer are able to function effectively.

For a behavior to be truly compulsive it must be something a person doesn't really want to do yet feels powerless to stop. Lining things up, insisting on eating certain foods and not tasting others, entering rooms from a specific door or tantruming if things are changed are some examples of compulsive behavior in special children. For the special child, the compulsive behavior seems to provide a kind of comfort and security. It is as if the child is bringing order to a chaotic world.

Special children are characterized by the difficulty they have in learning new things. For them, failure and an inability to attain goals in a competitive society are commonplace. As a consequence, they learn to do what seems "safe" and are unwilling to try new things

that might result in failure or worse. *The resulting inflexibility can easily be misperceived as compulsive behavior.*

For example, a child is taught to use counters to solve a math problem. After a while, the parent or teacher wants the child to use a calculator instead. The child, however, feeling secure with the counters, vigorously resists the change. It is a resistance borne of fear and not of stubbornness or anger. Understanding the child's need for security is important when trying to modify seemingly compulsive behaviors. Change must be gradually introduced and the child's fears—whatever they are—need to be addressed.

Some compulsive behaviors—rocking, hand flapping or other self-stimulatory behaviors—often have a *neurological component.* Even though these behaviors can appear to have a calming effect, the rocking and similar actions can significantly hamper learning and stigmatize the child. These behaviors tend to be highly resistant to change; parents can face great frustration when trying to eliminate them. It is tempting to punish the child for this behavior, but such an approach is usually ineffective.

A more productive aproach is to substitute a more desirable behavior for the one you wish to extinguish. One way of accomplishing this is by selectively reinforcing the desired behavior. For example, sitting quietly in a chair is typically more desirable than rocking. Thus, the parent or teacher rewards the child only when he or she is sitting appropriately. At first, the amount of time that the child is able to sit still may be very limited, requiring some physical prompting if necessary—holding the child still, for instance. The child should be given a reward such as verbal praise or a food tidbit, even if the sitting period is very brief. Gradually increase the amount of time required in order to get the treat until the child can sit still without rocking. A behavioral specialist can help to develop a program to fit your child's particular needs.

Remember, compulsive and ritualistic behaviors are difficult to modify. Doing so calls for patience, understanding and, more often than not, professional guidance.

Illustrations by Leah Spring